Involving a young person in the development of a digital resource in nurse education

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ABSTRACT

Health policies across western societies have embedded the need for service user and carer perspectives in service design and delivery of educational programmes. There is a growing recognition of the need to include the perspectives of children and young people as service users in the design and delivery of child focused educational programmes. Digital storytelling provides a strategy for student nurses to gain insight into the lived experiences of children and young people. Engaging with these stories enables students to develop an understanding of a young persons' experience of healthcare. This paper outlines a project that developed a digital learning object based upon a young person's experience of cancer and student evaluations of the digital learning object as a teaching and learning strategy. Over 80% of students rated the digital learning object as interesting and were motivated to explore its content. In addition, the evaluation highlighted that listening to the young person's experiences of her treatment regimes was informative and assisted understanding of a patients' perspective of care delivery.

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Introduction

In the United Kingdom (UK) Involving children and young people as service users is becoming increasingly acknowledged as best practice. Evidence suggests that children and young people can effectively contribute to the quality of health service development and models of care delivery, however safeguarding children and young people must remain paramount to the success of any participation initiative (Royal College of Paediatrics and Child Health (RCPCH) 2010). Little is known about the best way to involve children and young people as services users; possible methods of engagement include questionnaires, surveys, focus and advisory groups and the use of mystery shoppers (RCPCH 2010). Engaging effectively with children and young people requires a range of skills and tools in order to address the diverse perspectives, experiences, expectations and interests of this population (Smith et al., 2008). In addition, the age and developmental stage of the child and young person needs consideration.

The project discussed in this article was undertaken within a large School of Nursing in the North West of England. The school has 100 undergraduate children's and young people's nursing students studying for a degree in Nursing in their specific field of practice. In addition there is a significant number of Nursing and Midwifery Council (NMC) registered children's nurses engaged in continuing professional development.

There is a history of service user involvement within the school and a biennial forum is held where service users and carers are invited to share their experiences of healthcare with the pre-registration undergraduate students. The forum is attended predominantly by adult service users, with limited involvement from children and young people. One reason for this limited involvement may relate to the difficulties children and young people may have when communicating perspectives of their illness to healthcare providers (Woodgate, 2008). In addition, the transition between being a dependent child and an independent young adult can increase feelings of vulnerability affecting the engagement of young people in service user initiatives (Olsen and Harder, 2009). This paper will describe the development and evaluation of a digital resource which was designed as an approach to engaging a young person in the schools service user initiative.

Service user involvement in health education

Service users are a rich source of stories that can benefit healthcare related practice as they are best placed to discuss their medical conditions and the affect these have had on their lives (Davies and Lunn, 2009; Haigh and Hardy, 2010). Listening to patients' experiences is a potent way of exposing students to the human experience, encouraging sensitive, individualised and compassionate practice (Christiansen, 2010). Equally, patients

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enjoy being involved in contributing to student curricula (Davies and Lunn, 2009). Nurses in the United Kingdom (UK) are required by their professional body to advocate for patients, by listening and responding to their preferences and helping them access relevant services (Nursing and Midwifery Council (NMC), 2008). Hearing patient perspectives can assist students to develop an understanding of patients' needs thus encouraging the skills of advocacy.

The United Kingdom (UK) government has demonstrated a commitment to service user involvement with the creation of an independent consumer champion, Health Watch England (DH, 2010). This champion has responsibility for ensuring that the voices of service users, including children and young people, are acknowledged as part of local commissioning of services, ensuring their specific needs are taken into account. Globally, governments have a duty to ensure that young people have an opportunity to express themselves and ensure their views are given weight according to their age and maturity (World Health Organisation, 2003).

Active engagement with children and young people is particularly evident within the field of childhood cancers. The emergence of a range of childhood cancer organisations globally (Box 1) demonstrates a commitment to ensuring that the views of children and young people with cancer are heard and influence practice. In addition, nursing evaluations of healthcare are an essential element of clinical practice and an integral component in the education of students (Davies and Lunn, 2009).

A recent review of pre-registration nurse education in the UK (NMC, 2010) led to new Standards that included a greater emphasis upon the importance of service user involvement. The Standards advise that where possible, children's nurses must ensure that children and young people are actively involved in decision making and able to make informed choices about all aspects of their care.

Higher education providers have a responsibility to consider how curriculum design and teaching and assessment strategies add value to the student experience and how these affect their functioning (Gutteridge and Dobbins, 2010). As burgeoning professionals, student nurses are required to develop an understanding of service users as key stakeholders of health services. Incorporating patient perspectives into the nurse curricula using methods such as digital stories enables students to hear authentic accounts from service users assisting them to reflect upon the skills required to effectively engage with children and young people.

Digital learning objects

Emerging technologies and accessible information are important challenges for Universities who need to develop teaching and learning practices that meet the needs of learners (Johnson et al., 2010). Access to the internet via mobile technology allows students to engage with learning resources at times and locations that suit them best. The expansion of the world wide web has resulted in the development of a range of educational resources, including digital learning objects (DLO's). Digital learning objects are pre-

developed digital activities that can be integrated into educational programmes with a focus upon capturing a story (Billings, 2010). Digital stories are short multimedia presentations that may include a combination of personal narratives, images and music to create unique and potentially emotional accounts of patients' experiences of healthcare (Christiansen, 2010). These digital learning resources are described as unique opportunities that enable others to walk in the shoes of the storyteller (Stacey and Hardy, 2010).

Reported benefits of DLO's include educational content and activities that can be reconfigured depending upon the context, and managed within a virtual learning environment (Lane and McAndrew, 2010). Lecturers and students are able to use DLO's as and when necessary, resulting in reusable learning objects (RLO's). As a result, RLO's are becoming more commonplace in nursing and medical education and offer a useful method of engaging service users in educational initiatives (Blake, 2010).

Project

The aim of the project was to develop and embed a digital learning object within taught modules in order to expose students to the lived experience of a young person with a life threatening condition and evaluate students' perceptions of this as a teaching and learning tool.

An opportunity to develop this DLO arose when a young person, Maya, agreed to speak to a cohort of final year pre-registration students studying children's nursing. Maya had been diagnosed with leukaemia three years previously, at the age of seventeen, and had recently completed a three-year course of treatment in an adult care setting. Initially Maya attended university to share her experience of healthcare with nursing students and described this encounter as enjoyable and cathartic.

Evaluations from the students highlighted the value of listening to Maya's story reporting that it had enabled them to gain insight and develop empathy with her experience as a young person with a life threatening condition. Although Maya was enthusiastic about her previous contribution to the nursing curricula she did not feel able to continue contributing on a long term basis. Capturing Maya's experience as a digital learning object not only enabled her story to be saved for future use but also addressed several module and programme outcomes (Box 2).

Ethics

Consent to take part in the DLO was given both verbally and in writing by Maya. Only students registered on the modules within the nursing programmes are able to access the DLO. Maya was aware of the purpose and permanency of the DLO and was involved in agreeing the content and reviewing the final product.

Methods of capturing Maya's story were discussed with the University's information technology department and a digital

Box 1
Organisations for childhood cancers.

> Teenage Cancer Trust (www.teenagecancertrust.org)
> Teenagers and Young Adults with Cancer (www.TYAC.org.uk)
> American Childhood Cancer Organization (www.acco.org)
> Can Teen (www.Canteen.org.au) in Australia

Box 2
Programme/module learning outcomes.

> 1. To reflect upon practice in relation to the family and child with complex needs;
> 2. Interpret and utilise data and technology in theory and practice;
> 3. Develop practitioners who are able to consider the healthcare needs of patients in a variety of settings;
> 4. Facilitate knowledge, skills and attitude necessary to promote equality and diversity when interacting patients.